



Hierarchies of knowledge in responses to messages of newbies in online health support groups

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ABSTRACT

Objectives: To determine how hierarchies of knowledge are established in two online health forums: one for recovery from eating disorders and the other for diabetes.

Methods: 28 threads, with a total of 55,462 words were collected from the eating disorders (ED) forum. From the diabetes (D) forum, 18 threads were extracted, with a total of 51,397 words.

We performed a quantitative and a qualitative analysis of the structures and mechanisms to convey experiential knowledge and to deliver advice.

Results: The frequency of strategies such as providing facts about the illness, sharing personal stories and using medical terminology was higher in the diabetes forum than in the eating disorder forum. In the category of providing advice, ED and D responders behaved as experts and formulated advice in an authoritative way by resorting to imperatives and deontics of obligation.

Conclusion: In both fora, epistemic and emotional experiences are presented. The goal in each site is the creation of shared understanding among their members. Experiential knowledge is highly personal, and it is never depicted as antagonistic to medical expertise.

Practice Implications: Experiential knowledge is complex and rich and can complement medical expertise in the treatment of long-term and/or chronic health conditions.

1. Introduction

1.1. Background

Online health forums represent a form of interactive communication within a group of individuals who share a similar lived experience [1]. Forum users engage in asynchronous, text-based discussions in which information, advice and emotional support are exchanged [2–10]. In an online peer support community, voicing the lived experience of the illness is the essence of the messages exchanged. The process of sharing might adopt different forms, from offering long life stories that report the onset and development of the health condition, to the narration of the multiple medical visits to get a diagnosis [11]. Responses to these narratives serve to reanalyze, rephrase, and retell the story from different perspectives and with different insights. These dialogues provide comfort, opinions, or advice, but they also deliver different versions

of the truth. The subjective experience of each person is transformed into experiential knowledge, which is a kind of outcome of reflexivity on one's personal experience [11].

The nature of experiential knowledge, and its potential to improve the outcomes of traditional treatments [12], has been the focus of investigation in recent years in the areas of social science and mental health [13–15]. The growing interest for experiential knowledge stems from the increasing importance of the role of patients' experiences as the grounds for decision-making in the medical field. Since online forums are now the space in which patients share and spread their experiential knowledge, three main questions arise: (1) what kind of information is exchanged in these forums; (2) who takes up the role of an expert in online health support groups; and (3) how hierarchies of knowing are established and negotiated in these sites.

In relation to the nature of the information traded in discussion threads, several studies have concluded that online support groups for

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mental health conditions (e.g., depression, schizophrenia, eating disorders, among others) present a high number of emotional posts [16–18]. Instead, online support forums for individuals suffering from diabetes largely focused on providing informational aid to recognize, understand and manage the symptoms, with a focus on managing the condition, rather than curing it [17].

Regarding the issue of who is a peer expert, there is an extensive body of research dedicated to systematizing the kind of strategies displayed to construct expertise in online health forums [19–27]. However, there is still a scarcity of studies exploring the categories of knowledge shared in these communities.

1.2. Aims

Within this framework, we focused our attention on the first message posted by new members (newbies) and its responses in two different Spanish online fora: a support group for diabetes (D forum) and a support group for eating disorders (ED forum). These first messages are particularly important since they are often posted by recently diagnosed individuals, or by individuals who are still awaiting diagnosis and who have a lot of questions or –more often in the case of diabetes – individuals who must start a new treatment (but may have been diagnosed for a long time). The responses, in turn, convey the experiential expertise of each forum member.

Both diabetes and eating disorders were selected for comparison in the present study because the main features that differentiate each condition shape the ways in which knowledge of the illness is produced and delivered. Diabetes is a physical chronic condition (except the gestational variant), whereas eating disorders qualify as psychological conditions (with severe physical effects) from which the person must recover through a clinical intervention. Considering these distinctions, the specific aim of our study is to determine which strategies are used to convey expertise, according to the health condition being invoked, and what hierarchies of knowledge, if any, can be recognized.

2. Methods

2.1. Corpus

Two publicly available specialized patient fora in Spanish were selected: one for recovery from eating disorders and the other for diabetes. For sampling, we selected those threads in which the first poster was a newbie who was requesting advice, asking for opinions or information, or disclosing a problem. Only threads with more than 10 responses offered to the advice solicitation were considered. 28 threads, with a total of 55,462 words, were collected from the ED forum. From the D forum, 18 threads were extracted, with a total of 51,397 words. We narrowed the sample to posts written by patients and addressed to other patients using the forum. Other messages posted by friends or relatives were discarded. The excerpts will be reproduced as posted, including possible non-standard language use.

The two online fora examined in this study are public sites. It is not necessary to register and to sign in to get access to the messages posted. In addition, participants in both fora use a nickname, and, hence, their identity is concealed. To further protect participants' anonymity, no nicknames or any other information that could identify the person will be mentioned in this paper. Thus, identifying information in the posts (such as concrete personal medical data) was removed. In addition, the excerpts from the posts cited in this study have been shortened to protect anonymity. For the same reason, we will not refer to the forum websites by their name. The data collection from the ED forum and the D forum were approved, respectively, by the University of Barcelona's Bioethics Commission (CBUB) and by the ethical committee of the Institute of Language and Communication of the Université catholique de Louvain.

2.2. Procedure and analysis

We identified structures and mechanisms deployed by responders to newbies' posts in both sites to highlight experiential knowledge. We focused on specific constructions already identified in the literature with a view to comparing their realization in the two selected fora [4–7, 28]. The list of strategies was coded according to the following set of information categories:

1. Facts:

Following [29], a “fact is something that can be checked and backed up with evidence”; that is, it can be verified. However, users of both sites are not medical experts, and, hence, some of the claims found in the responses may not be completely true. In any case, we define the category of facts in the present study as those claims that are introduced as factual statements about the illness. They are usually expressed resorting to the third person and in present tense. They are conveyed as the truths of the experience with the condition.

2. Second stories:

Responders usually resort to second stories to offer their account of a similar experience. Second stories include similar focal aspects of the experience as the one told by the newbie in her/his first post, but they often provide a different perspective to the story. These personal accounts might be used to show alignment and affiliation (i.e., epistemic symmetry) or to provide the basis for sound advice [6,28].

3. Healthcare professional mentioned as an information source:

Referrals to healthcare professionals following the request for advice were considered to evaluate the role that users of both fora assign to medical experts [30,31].

4. Providing advice:

Forum users invest significant efforts to give advice to others [5,6, 22,32,33]. Advice provision implies a certain imposition from the advisor upon the advisee [34], due to the asymmetric relationship of authority and expertise (the imbalance in knowledge) between the interactants [35]. The advice can be delivered either directly (resorting to direct commands, for instance) or indirectly (with mitigation strategies).

5. Use of medical/clinical terminology:

Given the role that regular participants in online health fora play in managing their own conditions, some researchers have argued that they “should be recognized as health-care professionals' medical collaborators” [36]. Thus, the kind of knowledge exhibited by online patients is not restricted to “experiential knowledge”, but includes medical knowledge, as demonstrated by using specialized terminology.

6. Offering resources to deal with the illness:

One way of sharing resources to manage the condition was signposting other information, such as providing links to external websites, blogs, videos, referring to lists of treatment centers shared in the site, or directing to other areas of the forum [30]. These are cases of ‘manifest intertextuality’ [37] where the poster explicitly refers to other texts as helpful information, thus conferring them authority. However, other strategies are situated in the realm of interdiscursivity constituting “a discourse type (...) through a combination of elements of orders of discourse” [37], e.g., using specialized terminology as a way of combining elements of other discourses (such as consultations with professionals) in the forum messages.

7. Normalizing symptoms:

Often members of online health communities talk about “typical behaviors” of the illness, particularly in the case of mental conditions [20]. Normalizing symptoms is defined here as any explicit attempt to establish whether a specific behavior or experience is a bona fide symptom of diabetes or eating disorders, either through resorting to authoritative claims (what doctors, clinicians, researchers say) or through personal experience [20].

8. Supporting other members' responses:

Regular participants in the ED forum and the diabetes forum engage in distributed knowledge processes by which they cooperate to build, distribute, share and use information [38]. One strategy that contributes to co-create authoritative knowledge is backing each other's claims when replying to newbies' requests for assistance.

The data were analyzed quantitatively by means of descriptive statistics. The number of posts containing each strategy was counted and percentages were calculated (see Table 1 in Section 3). When separately coding a representative sample of the data, the authors reached an intercoder reliability of 0.782 (Krippendorff's Alpha), which can be considered an acceptable agreement. The quantitative analysis was complemented with a qualitative analysis of the utility of each strategy to demonstrate experiential knowledge in the two online communities under study.

3. Results

The codification of the responses offered to newbies in both fora, according to the categories established and detailed in Section 2.2, yielded the results gathered in Table 1.

Responses to newcomers in the ED forum can come from members who are still struggling with the illness and from those who are ahead in recovery. The latter are senior members because they have been contributors for a long time, know each other (some of them have even met in person), and have become moderators of the forum. These more experienced members combine all the strategies listed in Table 1. Further, the responses by experienced members are in accordance with the qualifications, degree of knowledge, and newbies' disposition to fight the illness and accept medical treatment. Therefore, the components, structure and content (emotional and informational) of the responses offered to each group of ED newbies (new to the ED, deniers of the condition, experienced ED sufferers who have relapsed), are different. In the diabetes forum, however, the situation is different. Given that participants may have already had diabetes for a long time already but are entering a new type of treatment, they sometimes seek expertise of participants with less experience with the illness itself but more experience with a specific treatment (e.g., type of insulin, sensor for continuous glucose monitoring). Expertise is then better exhibited in relation to a particular topic, with a participant potentially being an expert in one thread but not in other one.

Giving advice is the most common category in the ED responses (25.6 %), including advice to contact a professional. Recommendations to experienced newbies tend to be indirect or mitigated (13.9 % of the cases), which means resorting to conditionals and modal verbs (e.g., *you could check your fasting glucose with your glucose meter* as a more mitigated advice than *check your glucose*, etc.), where the advice directed to complete newbies to the illness or to ED deniers is always to get treatment. This instruction is usually performed in a very direct, straightforward, and authoritative fashion, by resorting to imperatives (11.7 % of the strategies).

The act of providing advice is also present in 30 % of the diabetes responses. The use of direct vs. indirect advice generally depends on the content of the advice: directly formulated advice through imperatives mainly concerns the advice to consult a healthcare professional or more general lifestyle advice (e.g., eat healthily, exercise), whereas the more indirectly formulated advice focuses on the use of insulin, which is rather a sensitive topic since it can have a strong impact on the user's physical condition and requires a medical background, or advice in which the poster anticipates that this is perhaps a dispreferred answer to the initial poster's question.

The importance of receiving proper medical treatment is reinforced with the constant referral to healthcare professionals, which is the second most common category to exchange experiential knowledge in the ED sample (21.3 %), and the fifth in the diabetes forum (15.2 %). The

presence of these two categories in the responses to total newbies to the ED or to ambivalent experiencers who resist treatment are consistent with the two principles that rule conversations in the ED group: ED recovery is always possible (chronicity is not an option), and EDs require clinical interventions [39]. Both tenets are supported with a battery of statements, presented as indisputable facts of the disorder, that warn the newbie about how dangerous EDs are and how critical it is to undergo treatment.

In the case of diabetes, although recovery is not possible for the illness, adequate medical treatment contributes to a longer and better quality of life, so it is encouraged throughout the forum. Though some messages are critical about (specific) healthcare professionals, this criticism is never presented as a reason to abandon medical treatment, but rather to look for a more competent and/or more involved professional.

Factual claims represent the third most frequent category in the ED sample (14.8 %). They usually appear in the responses to complete newbies to the ED, and they are made by senior members. These claims are sometimes strengthened by other regular members who support them (8 % of the cases). In the diabetes forum, they represent the fourth category (25.6 %) and rather concern information sharing.

When, instead, responses target the messages posted by experienced newbies, senior contributors to the site tend to warrant their advice by appealing to common knowledge, based on shared experiences. This common ground is built on personal accounts of ED symptoms, phases of recovery, thoughts, behaviors or practices. These second stories that confirm, expand or rephrase key aspects of the newcomer's first post represent the fourth most common strategy in the ED forum (15.4 % of total cases). In addition, experiential knowledge is also demonstrated in the responses to newbies by deploying medical terminology (9.3 % of the sample), particularly in those cases in which the first poster uses herself/himself such language (which proves experience with the ED).

In the diabetes forum, second stories are the third most common strategy, with 30.4 % of the responses containing them. Their use is however less linked to whether the initial poster is new or not, but it is rather connected with specific questions concerning the treatment, e.g. the impact of certain insulin types or food on glucose levels. Thus, the users narrate their personal experience leading to their current strategies and 'tips', which are then presented as the outcome of a learning process, for which the starting point was often like that of the initial poster.

The strategy for which the quantitative analysis yields the major difference between both fora is the use of medical terminology, which is overwhelmingly present in the diabetes forum (45.2 %) and much less in the ED forum (9.3 %). This very large use in the diabetes forum is partly due to the need of such terminology to discuss one's everyday physical state (e.g. *hypoglycaemia*) but also possible treatments (e.g. insulin types). Note that while in some cases this terminology is employed as given shared knowledge of the community, in other cases it is deployed to explain certain concepts to the new posters, thus fulfilling an important role in knowledge transmission and popularization.

4. Conclusions

The comparative study of linguistic strategies to construct an expert status and hierarchies of knowledge in an ED and a diabetes forum yielded the following results. In the first place, the fact that an ED is conceived as an illness from which one can recover, as opposed to the chronic nature of diabetes has an impact on how expertise is produced in both fora. For ED experiencers, those who have recovered are defined and interact as experts, whereas for D patients, expertise is built over time. What is more, being an expert managing diabetes depends on contextual factors, such as undergoing specific treatments and dealing with evolving situations regarding the illness.

In the second place, although similar strategies can be identified in both fora, such as advice giving, personal stories, reference to healthcare professionals, or mentioning facts, there are slightly different degrees of

Table 1
Categories of experiential knowledge in the ED and diabetes forum.

Type of strategy	ED forum			Diabetes forum		
	Number of responses containing the strategy	Percentage	Example	Number of responses containing the strategy	Percentage	Example
Facts	48	14.8 %	La cronicidad no consiste en recuperarse y presentar posteriormente recaídas, sino, estando en tratamiento, no obtener mejoría clara. <i>Chronicity does not mean that [the person] first recovers and then relapses, but rather that [she/he] is in treatment and there is no improvement.</i>	79	25.6 %	La tipo 1 es autoinmune [further description], la tipo 2 y gestacional aparecen por una resistencia a la insulina. <i>Type 1 is autoimmune [further description], type 2 and gestational diabetes appear because of a resistance to insulin.</i>
Personal stories	50	15.4 %	Hace muchos años, [further description] tenía muchísima distorsión corporal. Me veía obesa y estaba literalmente en los huesos. No tuve tratamiento y tenía 11 años, [further description] así empezó mi convivencia de más de 20 años con el TCA. <i>Many years ago, [further description] I had bad dysmorphia. I felt obese and I was nothing but skin and bones. I didn't get any treatment. I was 11 years old. [further description] That is the way my life with ED started. It's been over twenty years now.</i>	94	30.4 %	En mi caso me lo detectaron muy tarde y paso muy poco tiempo. Según el médico me ayudo mucho q hacía deporte regularmente (...) Mi día a día no ha cambiado nada, salvó lógicamente la insulina y los controles. <i>In my case they detected it very late and very little time passed. According to my doctor the fact that I regularly did a lot of sport helped me a lot (...) My everyday life hasn't change at all, except logically the insulin and controls.</i>
Healthcare professionals mentioned	69	21.3 %	No creo en la curación sin tratamiento psicológico específico, pero sí creo en la recuperación completa. Pero, para ello es el terapeuta el que debe dar por finalizado el tratamiento. <i>I don't believe in complete recovery without specialized psychological treatment. But for that to happen the therapist is the one who must put an end to the treatment.</i>	47	15.2 %	No lo dejes, vete al endocrino en cuanto puedas, no es saludable tener esos niveles. <i>Don't leave it [like that], go to the endocrinologist as soon as you can, it's not healthy to have those levels.</i>
Giving advice Direct Indirect	38	11.7 %	Busca el coraje que necesites, pero busca ayuda y ponte en tratamiento , no te engañes con excusas <i>Find the courage you need but look for help and get treatment. Don't fool yourself with excuses.</i> Si no te estás tratando, deberías porque esto no es una tontería <i>If you are not in treatment, you should be, because this is not a small thing</i> El SII es un diagnóstico de exclusión, es decir, hay que descartar las enfermedades que producen síntomas parecidos (enfermedad celíaca, enfermedades inflamatorias... [further description]) <i>IBS is a diagnosis of exclusion, which means that other illnesses that present similar symptoms (celiac disease, inflammatory diseases) have been ruled out.</i> [further description]	40	12.9 %	Habla con tu especialista, tendrá que ajustarte la dosis. <i>Talk to your specialist, (s)he will have to adapt your dose.</i> Podrías tu misma con glucómetro checar tu glucosa en ayunas, y luego 2 horas después de comer. <i>You could check your fasting glucose yourself with a glucometer, and then 2 hours after having eaten.</i>
	45	13.9 %		50	16.1 %	
Medical terminology	30	9.3 %	El SII es un diagnóstico de exclusión, es decir, hay que descartar las enfermedades que producen síntomas parecidos (enfermedad celíaca, enfermedades inflamatorias... [further description]) <i>IBS is a diagnosis of exclusion, which means that other illnesses that present similar symptoms (celiac disease, inflammatory diseases) have been ruled out.</i> [further description]	140	45.2 %	Debuté con [concrete number] de glico, cetoacidosis y [concrete number] mg/dL en ayunas. El péptido C en [concrete number]. <i>I started with [concrete number] glycemic, ketoacidosis and [concrete number]mg/dL when fasting. C-peptide at [concrete number].</i>
Offering resources	12	3.7 %	Te dejo aquí una lista de centros, asociaciones, etc. para que busques qué te queda cerca de donde vives <i>I leave you here a list of treatment centers, associations, etc. for you to find which one is near where you live</i>	24	7.7 %	Yo uso desde que salió una aplicación para el móvil que se llama [application name anonymized] donde me indica según la cantidad del alimento en cuestión, hidratos de carbono, grasas y proteínas. <i>Since it came out, I use a mobile phone app that is called [application name anonymized] where it indicates according to the quantity of the food in question the carbohydrates, fats and proteins.</i>
Normalizing symptoms	6	1.9 %	Todo lo que cuentas es absolutamente normal en el inicio del tratamiento y la renutrición <i>Everything you say is normal at the beginning of the treatment and the refeeding process</i>	9	2.9 %	Es totalmente normal. <i>It's completely normal.</i>
Supporting other members' claims	26	8 %	en la experiencia hay coincidencia en que, como dijo [anonymized other user], se trata de un memento de renuncia <i>In the experience [of recovering from an ED]</i>	1	0 %	Como te han dicho, hay un montón de formas de proteger el Freestyle (...). <i>As they've told you, there are lots of ways to protect the Freestyle (...).</i>

(continued on next page)

Table 1 (continued)

Type of strategy	ED forum			Diabetes forum		
	Number of responses containing the strategy	Percentage	Example	Number of responses containing the strategy	Percentage	Example
			everybody agrees that, as [anonymized other user] said, there is a moment of surrendering			
Total number	324	100 %		309	100 %	

dominance, especially concerning the use of medical terminology (particularly in the D forum) and supporting other forum members' contributions (in the ED forum).

In the third place, responses in both fora overall make a strong case for seeking or continuing professional medical treatment. This support is present both in the frequent mentioning of healthcare professionals and in the advice-giving act, which often includes a strong encouragement or incitation to seek, maintain or improve treatment. This result goes against the negative views that sometimes are voiced in the literature concerning the quality of the health information available online. Our analysis confirms the idea that the experiential knowledge shared and exchanged by forum members can be considered as a supplement to the assistance provided by healthcare professionals (cf. [36]).

Peer expertise complements the medical and clinical practice by (i) making medical information more accessible to laypersons (as reflected in the fact the forum members deliver factual claims and use medical terminology when providing assistance to others); (ii) being available when healthcare professionals are not, due to economic issues, working hours or healthcare waiting lists; and (iii) contributing with first-hand knowledge anchored in a concrete lived experience, which is information of a different nature than the more abstract scientific knowledge found in the medical community.

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CRedit authorship contribution statement

Carolina Figueras Bates: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing. **Barbara De Cock:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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